

PEER REVIEW HISTORY

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ARTICLE DETAILS

TITLE (PROVISIONAL)	'Timely' Diagnosis of Dementia: What does it mean? A narrative analysis of GPs' accounts
AUTHORS	Dhedhi, Saadia ; Swinglehurst, Deborah; Russell, Jill

VERSION 1 - REVIEW

REVIEWER	<p>Professor Carol Brayne Institute of Public Health University of Cambridge England</p> <p>I have written articles on this topic area including the need for improvement of the evidence base to support any specific policies which introduce activities akin to screening.</p>
REVIEW RETURNED	19-Dec-2013

GENERAL COMMENTS	<p>This is a welcome 'step back' paper which looks in a measured manner at the terms used in the current rhetoric surrounding diagnosis of dementia and the reality on the ground from a GP perspective. The work is carefully justified and clearly outlined. The gap between rhetoric and the reality appears to be as large, as suspected in the rather heated ongoing debate. From a social science public perspective, the recent attention to dementia has been based on terms without clear articulation of what "early" means. This paper fills this gap in current evidence, and itself very timely for both national and international audiences. Reservations and limitations are covered including the bias potentially in using an academic general practice setting rather than a more 'usual' one (if such a thing exists). The meaning of a diagnosis has clearly come to be something different or the research/policy/advocates within society when compared with this primary care perspective. This is well covered in the discussion. Current advocates of early diagnosis might suggest this piece does not articulate what they perceive to be the self evident of benefits but the article does not really seek to cover that part of the debate. The references might need a little updating to capture more recent discussions e.g. Le Couteur et al.</p> <p>The paper should be reviewed by an experienced qualitative researcher as well as content experts.</p>
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REVIEWER	<p>Constance Dimity Pond Discipline of General Practice, Faculty of Health University of Newcastle Australia</p> <p>I have been on advisory boards for a number of pharmaceutical</p>
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REVIEW RETURNED	24-Dec-2013

GENERAL COMMENTS	<p>This is a very interesting small qualitative study about the diagnosis of dementia in general practice. It is very thoughtful and provides new information about the diagnostic process in general practice in relation to dementia. However I have a few issues with it:</p> <p>1. I would like to see the interview guide or schedule. The interview process is described in a paragraph in the methods, and this is fine, but there does not appear to be a question about "timeliness" or how "opportune" the diagnosis was in the described process. I am interested in whether this appeared as a prompt in the interview schedule, or was otherwise in some way elicited from the respondents, or whether it emerged from the interviews without prompting.</p> <p>2. The study states that the interviews were done by a student researcher who interviewed practising GPs in an academic department. The principle of reflexivity in qualitative research would suggest that there should be some consideration of the relationship between this student researcher and the academics. For example, might these academics be reluctant to discuss diagnostic failures with a student researcher? Might they adopt a "teaching" stance in their discussions? Might this group of academics be very reflective practitioners in this context compared with the average street corner GP? I would like to see some additional thoughts on this issue.</p> <p>3. Conclusions drawn were rich and fascinating, and justified by the quotations given. However, there was no consideration of an alternative explanation of the government policy ie that a significant number of cases of dementia are simply not identified AT ALL by GPs. Sadly, there is good research evidence that this is the case worldwide. In our own work (submitted but not yet accepted) GPs were asked to identify whether the study participants had "possible, probable or definite dementia" and many of those with dementia on the diagnostic study interviews/instruments (in some cases relatively well advanced) were not identified at all, even as possible dementia. I would hasten to add that brief screening instruments have a similar shortfall in diagnosis, as well as a tendency to overdiagnose. The study here reports a tension between "knowing" and "not knowing" but in all cases reported the GP had some inkling at least that the patient had dementia, and the diagnostic process - including disclosing the diagnosis or not - took off from there. Perhaps the instruction to respondents to think of a relevant case, plus the relationship with the student researcher, ensured that there were no reports of failure to identify dementia to disconfirm the study findings. I would be interested in the team's comments on this.</p>
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VERSION 1 – AUTHOR RESPONSE

Reviewer 1. Professor Carol Brayne

1) Current advocates of early diagnosis might suggest this piece does not articulate what they perceive to be the self evident of benefits but the article does not really seek to cover that part of the debate.

We agree that our paper does not discuss in detail the perceived 'self-evident' benefits of diagnosis, although we have summarised the arguments for (and against) early diagnosis as identified in previous research in Table 1. We have also drawn attention to the fact that early diagnosis is indeed reported by its advocates in terms that assume its benefits are axiomatic and taken-for-granted

(Introduction, P4). We also agree that detailing the benefits (or disbenefits) of early diagnosis was not the central aim of our research question here. Our interest was to learn how the notion of 'timely diagnosis' was constructed in the moment-by-moment unfolding of GPs' accounts, and by conducting a detailed analysis of the language they used to articulate how a 'timely' diagnosis might (or might not) differ from an 'early' diagnosis, since we had noticed a tendency to use these two descriptors synonymously in the policy literature.

2) The references might need a little updating to capture more recent discussions e.g. Le Couteur et al.

Thank you for pointing this out. We have included the reference to Le Couteur et al as suggested and made some minor amendments to the text to reflect this addition (page 4).

Reviewer 2. Constance Dimity Pond

1) I would like to see the interview guide or schedule. The interview process is described in a paragraph in the methods, and this is fine, but there does not appear to be a question about "timeliness" or how "opportune" the diagnosis was in the described process. I am interested in whether this appeared as a prompt in the interview schedule, or was otherwise in some way elicited from the respondents, or whether it emerged from the interviews without prompting.

Thank you for advising us of the need to be clearer about our interview approach. We have included the broad topic guide in Figure 1. You will see that neither 'timeliness' nor the concept of an 'opportune' time for diagnosis was referred to explicitly in the interview guide, since we wanted to explore how GPs make meaning in their own accounts. We have made some minor additional comments in the Methods section to make it clear that although a topic guide was used the approach also involved following the narrative threads pursued by participants. We have also included a final sentence in the Methods section to explain that the analytic themes are those which EMERGED from our iterative analysis of the data, and were not a priori themes explored during interview.

2) The study states that the interviews were done by a student researcher who interviewed practising GPs in an academic department. The principle of reflexivity in qualitative research would suggest that there should be some consideration of the relationship between this student researcher and the academics. For example, might these academics be reluctant to discuss diagnostic failures with a student researcher? Might they adopt a "teaching" stance in their discussions? Might this group of academics be very reflective practitioners in this context compared with the average street corner GP? I would like to see some additional thoughts on this issue.

We have introduced a paragraph in the discussion to incorporate our response to these concerns, in particular highlighting that the case for generalisability is not one we feel obliged to make in narrative research of this kind, whilst acknowledging that this is a small study with an 'atypical' group of GPs. Likewise we have included a sentence which discusses the possibility that academic GPs might somehow adopt a teaching stance when interviewed by a student. We found no evidence of this in our data.

3) Conclusions drawn were rich and fascinating, and justified by the quotations given. However, there was no consideration of an alternative explanation of the government policy i.e. that a significant number of cases of dementia are simply not identified AT ALL by GPs. Sadly, there is good research evidence that this is the case worldwide. In our own work (submitted but not yet accepted) GPs were asked to identify whether the study participants had "possible, probable or definite dementia" and many of those with dementia on the diagnostic study interviews/instruments (in some cases relatively well advanced) were not identified at all, even as possible dementia. I would hasten to add that brief

screening instruments have a similar shortfall in diagnosis, as well as a tendency to overdiagnose.

The study here reports a tension between "knowing" and "not knowing" but in all cases reported the GP had some inkling at least that the patient had dementia, and the diagnostic process - including disclosing the diagnosis or not - took off from there. Perhaps the instruction to respondents to think of a relevant case, plus the relationship with the student researcher, ensured that there were no reports of failure to identify dementia to disconfirm the study findings. I would be interested in the team's comments on this.

Thank you for these points. We are glad that you found the conclusions interesting and well justified by our data examples and analysis. Our interest in this particular piece of research was to explore the issue of disclosure and timeliness and what this means to general practitioners. This is a somewhat different issue to that which you identify i.e. a situation in which a GP simply has no inkling whatsoever that someone might have dementia in its very early stages. We adopted a narrative approach because of its strengths in terms of illuminating meaning and investigating how meanings are constructed. Given our interest in understanding GPs' perspectives and exploring how they construct 'timeliness' in their accounts it was helpful to focus on particular cases rather than abstract notions. This does indeed mean that we were investigating situations in which GPs were (at the very least) considering the possibility of a diagnosis of dementia. The issues raised by screening for dementia (rather than diagnosis) are related but somewhat different and are not central to our arguments in this paper. We have not made any amendments to our current paper in this respect but thank you for your observations and will look forward to reading your publication in due course.

VERSION 2 – REVIEW

REVIEWER	Constance Dimity Pond University of Newcastle, Australia I have served on advisory boards for a number of pharmaceutical companies, including Pfizer, Lundbeck and Elui-Lilly and more recently on the advisory board of Nutricia.
REVIEW RETURNED	04-Feb-2014
GENERAL COMMENTS	I think this is a well written, thoughtful paper and well worth publishing.